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Center for Urban and Regional Affairs

THE MINNESOTA RESPONSE TO AIDS

by Charles Backstrom and Leonard Robins

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TABLE OF CONTENTS

PREFACE

Charles Backstrom, Ph.D., is a professor of political science, University of Minnesota, Twin Cities campus. He teaches courses in Minnesota government and politics. He is co-author of *Tribune of the People: The Minnesota Legislature and its Leadership* (University of Minnesota Press, 1989), and *The Politics of Mental Health* (Columbia University Press, 1968).

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Robins and Backstrom are currently writing a book, *The Politics of AIDS* to be published by Chatham House. In connection with that project, they have surveyed chief health officers, legislative committee chairs, and hospital association executives in every state, and have conducted on-site visits with HIV/AIDS policymakers in five states besides Minnesota.

This study was supported by an interactive research grant from CURA and the Office of the Vice President for Academic Affairs, University of Minnesota. Interactive research grants have been created to encourage University faculty to carry out research projects that involve significant issues of public policy for the state and that includes interaction with community groups, agencies, and organizations in Minnesota. These grants are available to regular faculty members at the University of Minnesota and are awarded annually on a competitive basis.

The judgments expressed here are those of the authors, and should not be attributed to CURA, whose support we gratefully acknowledge.

INTRODUCTION

AIDS (Acquired Immune Deficiency Syndrome) is a specific group of diseases or conditions that opportunistically take hold during the severe suppression of the system that ordinarily protects people from those diseases caused by the human immunodeficiency virus (HIV). For this report, we will generally use the term HIV/AIDS to cover all phases of the disease, but where we are referring specifically to persons in the last phases of the disease, identified as diagnosed with AIDS, we will use the term AIDS only. People become infected with HIV/AIDS through sexual intercourse with a carrier of the virus, from sharing an injection drug needle with a carrier, from a transfusion of blood or blood products or receiving a transplanted organ from a person with HIV/AIDS, or (in a single case in the United States involving a dentist) from an infected health care worker to patients or (about forty cases nationwide) from a patient to a healthcare giver. It should be noted that actions taken in 1985 have essentially eliminated any current risk of receiving HIV/AIDS from a blood transfusion or organ transplant.

Because HIV/AIDS is a newly discovered disease, and because cases of HIV/AIDS in the United States have occurred overwhelmingly among persons often rejected by mainstream society—homosexuals (gay and bisexual men) and injection drug users—special problems occur in dealing with the disease. It is not surprising that demands arose for harsh or punitive policies that health authorities believed would be counterproductive to control of the disease. Also there was some resistance to positive programs against the disease if they could be even remotely considered as accepting homosexuality or drug use. Although Americans have traditionally been sympathetic to people with diseases, many make exceptions to those who have HIV/AIDS.

This report deals with major aspects of Minnesota policymaking on HIV/AIDS, specifically the response to HIV/AIDS of various Minnesota governmental and private institutions and groups and how the decisions about what to do came to be made.*

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* The authors thank more than fifty Minnesotans involved with HIV/AIDS policy who generously made time for extensive interviews. Their names are listed in Appendix A, but they are not cited specifically since we promised no direct quotation. Although most of the interviews were completed in 1989, a few noteworthy events since then are included, as well as various appropriations for fiscal year 1991.

HOW WIDESPREAD IS HIV/AIDS IN MINNESOTA?

As of the end of December 1990, 840 people had been diagnosed with HIV/AIDS in Minnesota. This is an increase of 186 cases in a year, adding more than a quarter more. Table 1 shows the year-by-year and cumulative AIDS cases in Minnesota. Cumulative cases are graphed in Figure 1.

Over 64 percent (540) of these people had died by the beginning of 1991. The eventual mortality rate will be much higher because AIDS is a progressively worsening disease. Table 1 also reports the number and percentage of deaths among those diagnosed with AIDS in Minnesota in any particular year. This shows that all of those diagnosed with AIDS more than five years ago have died.

The total deaths from AIDS is, of course, a small proportion of all deaths in Minnesota. Another way of looking at the data, however, is to see that AIDS is now the fifth leading cause of death among men aged twenty to sixty-four.

HIV/AIDS is an especially serious social and economic problem since most of its victims are younger. To comprehend the relative economic (not personal) cost of a disease, bio-statisticians calculate total years of potential life lost, that is, how many person-years before age sixty-five (a common age of retirement) were foregone by someone's early death. In 1988 alone in Minnesota, AIDS was responsible for 3.5 percent of potential years lost, the fifth leading cause. In 1989 AIDS accounted for 15 percent more of total years lost than the year before. Because of the concentration of AIDS cases in Minneapolis, AIDS was the leading cause of years lost by men in that city in 1989.

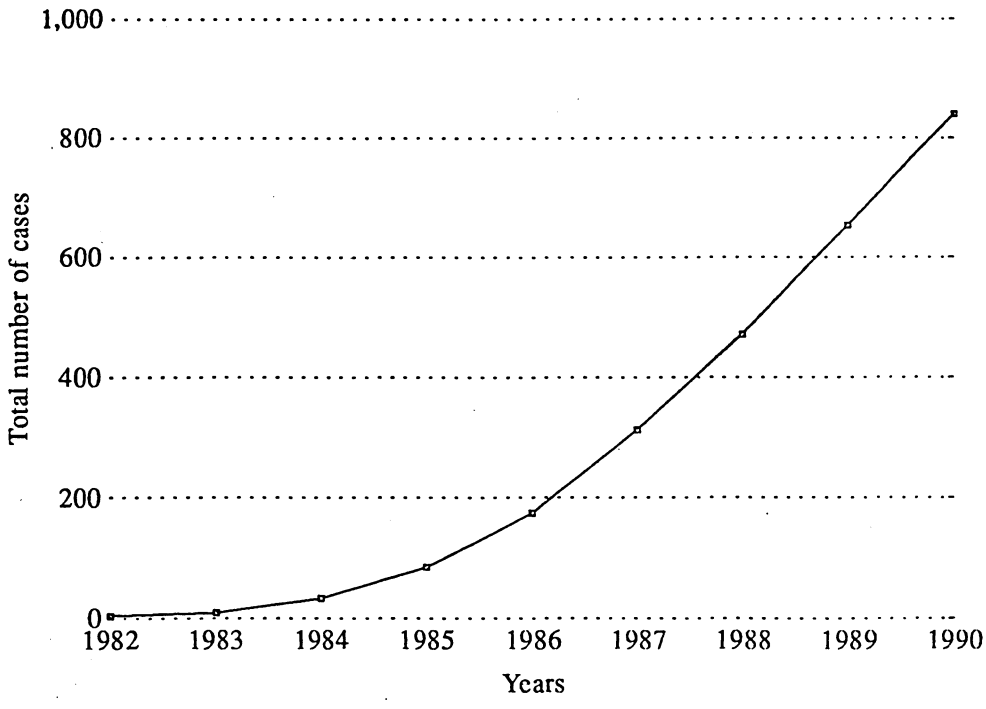
The total number of persons diagnosed with AIDS is not an adequate assessment of the extent of the disease. Many years will typically pass after infection before symptoms develop or evidence of the diseases constituting a diagnosis with AIDS appear. The number of AIDS cases in a given year therefore is an indication of how prevalent the infection was seven or eight years before. HIV/AIDS in Minnesota is actually much more widespread. As of November 1990, another 1,500 persons had been reported to carry the virus, but had not yet been diagnosed with AIDS. This is five times the number of people still alive with a diagnosis of AIDS (300).

Table 1. AIDS Cases in Minnesota

Year of Diagnosis	Number of Cases	Cumulative Cases	Number Dead	Fatality Rate
1982	4	4	4	100%
1983	5	9	5	100%
1984	24	33	24	100%
1985	52	85	52	100%
1986	90	175	82	91%
1987	138	313	123	89%
1988	158	471	110	70%
1989	183	654	93	51%
1990	186	840	47	25%
			540	64%

Source: Minnesota Department of Health, March 1991.

Figure 1. AIDS in Minnesota, Cumulative Cases



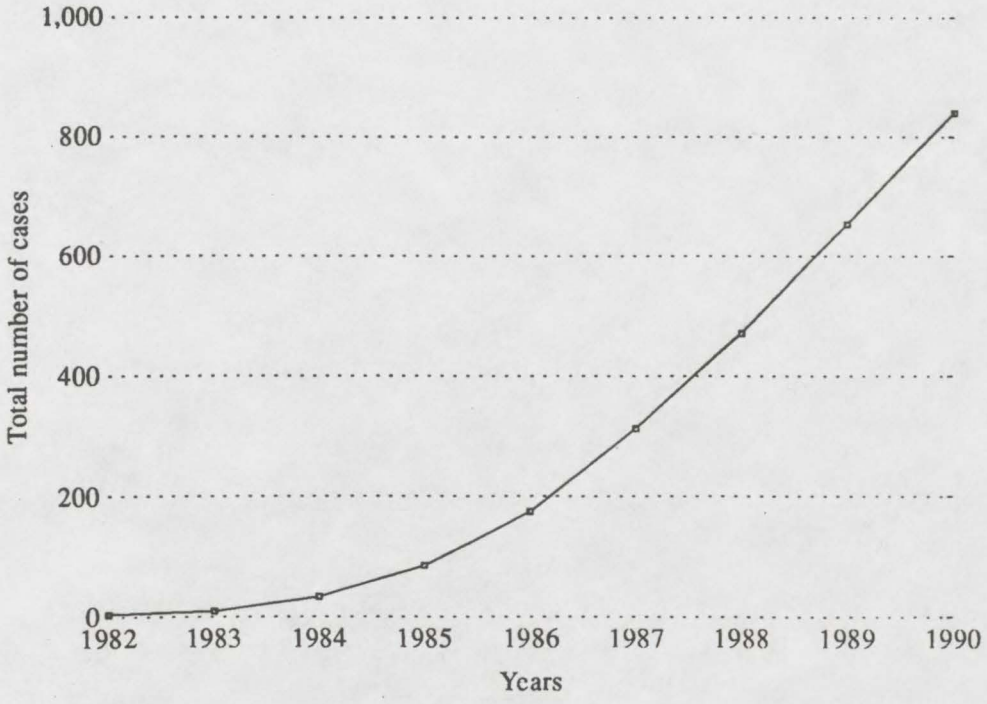
Moreover, because not all people infected with HIV/AIDS have been tested, the numbers of people carrying the virus is actually substantially higher than reported. The current estimate by Minnesota's Department of Health (MDH) of the number of infected people is at least 4,400, a number arrived at as a result of the cumulation of several estimates of the size of various populations at risk and prevalence of the virus in those populations. Even though this figure is considerably lower than initial estimates, three times the number who have tested positive for the virus actually carry it. Thus, even if no additional persons were to become infected, the number of AIDS cases will continue to grow. The Department of Health estimates that 200 new cases will appear in 1991, and 215 in 1992.

Almost 90 percent of Minnesota's AIDS cases are in the Twin Cities metropolitan area, 54 percent in Minneapolis alone. There is a wide variation in the presence of AIDS outside the metropolitan area. As of August 1991, thirty-one counties still report no cases, forty-seven report one to five, four report six to nineteen, and five report twenty or more (see map). These concentrations may reflect the relative attractiveness of living in various localities to persons with certain lifestyles, and certainly also indicate the desire of persons with AIDS to be near treatment centers and other support groups. But AIDS is becoming more common in greater Minnesota; although it had only 12 percent of the AIDS cases, it has 16 percent of those reported to be infected with the virus but not yet diagnosed with AIDS. Even these figures may be on the low side because people who were diagnosed in another state and came home do not show up in Minnesota's statistics.

How Does Minnesota Compare to Other States?

Minnesota ranks approximately in the middle among states in number of AIDS cases, but a more useful measure is the rate of infection in the overall population. In 1990 about 4.7 Minnesotans out of every 100,000 were diagnosed with AIDS. On this measure Minnesota ranks near the bottom. Six states, all in the Upper

Figure 1. AIDS in Minnesota, Cumulative Cases



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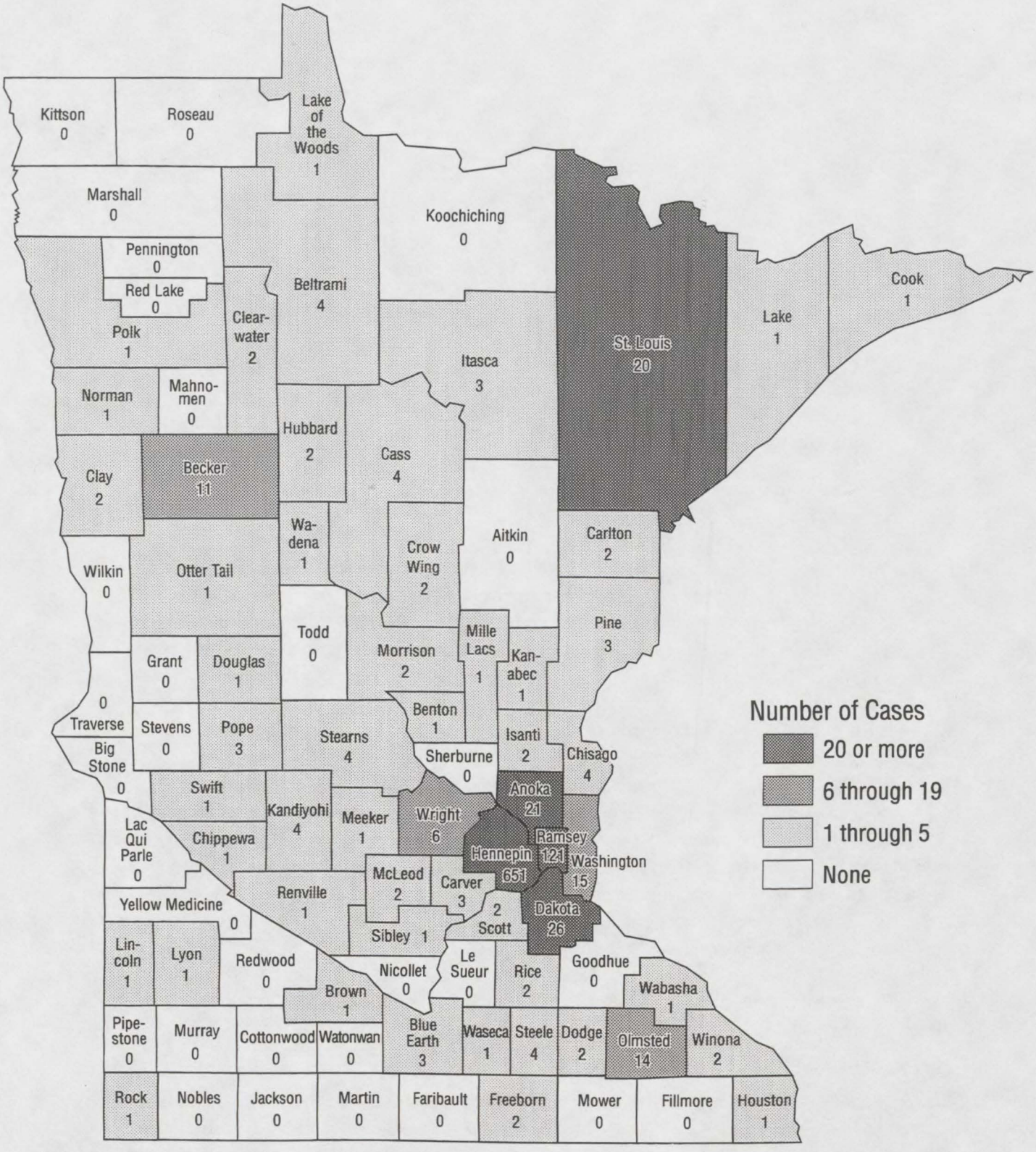
Cumulative AIDS Cases in Minnesota, August 1991



Midwest or Upper Mountain regions, have the lowest rates—all under 3 per 100,000. Other states in the mid-section of the United States have rates from 4 to 10, while the coastal states have the highest rates—19 in Texas, 25 in California, 31 in Florida and New Jersey, and 47 in New York.

The Minneapolis/St. Paul metropolitan area has a current AIDS diagnosis rate of 7.3 per 100,000, ranking it 18th from the *bottom* among areas with more than half a million people. For comparison, the rate in San Francisco is 131, New York City 84, Washington, D.C. 34, and Seattle 25.

Why is Minnesota's Rate Relatively Low?

The chances of a person acquiring HIV/AIDS depend upon how many people in the community already carry the virus, and upon how unsafe their own behavior is. Obviously, in a state like Minnesota where the number of infected people is still relatively low, even unsafe behavior is less likely to result in infection. In areas where the disease first got a foothold and where much unknowing risky behavior occurred, a large proportion of the people were infected. Unsafe behavior in those areas carries a high risk of picking up HIV/AIDS.

Moreover, because HIV/AIDS had a long headstart elsewhere and was well-covered in the media, Minnesotans have had more time to learn about how the disease is spread, and to take precautions if they wanted to, before HIV/AIDS became rampant here.

A survey of gay and bisexual men conducted for the Minnesota Department of Health in 1989-90 revealed that a majority claimed to have fewer partners and no risky sexual practices in the last year. But one-sixth reported engaging in risky behavior within the month.

In terms of acquiring HIV/AIDS through intravenous drug use, a smaller proportion of Minnesotans use intravenous drugs than in some other states—an estimated 3,000-5,000—and users are less likely to rely on "shooting galleries" where needles are commonly shared. Yet 1 percent of Minnesota high school students reported injecting steroids, and the vast majority of these shared needles.

WHO HAS AIDS IN MINNESOTA?

The sources of infection for people with AIDS are classified in Table 2, and shown graphically in Figure 2. Most cases of AIDS in Minnesota are found in homosexual and bisexual men, who account for four of five of the cumulative cases. It must be emphasized that HIV/AIDS is spread by unsafe *behavior* by anyone, not among certain *types* of people.

Intravenous drug users who are heterosexual account for fewer than one in thirty of the cases diagnosed in Minnesota. Nationally this figure has reached nearly a quarter of all new AIDS cases.

Homosexual men who are also intravenous drug users constitute almost one in seventeen cases of AIDS ever in Minnesota.

Females constitute under one in twenty-five of the AIDS cases in Minnesota. For females, intravenous drug use is the source of about one-seventh of their AIDS cases.

Heterosexual contact accounts for fewer than one in thirty of Minnesota cases, but half of female cases. About two in five of these female cases arise from sex with intravenous drug users.

Blood transfusions, blood components for hemophiliacs, or tissue transplants account for one in twenty-five AIDS cases in Minnesota, but this means of transmission has been rare since 1985 when testing blood for the virus antibodies was begun.

Children with AIDS constitute one in one hundred of Minnesota AIDS cases, numbering eight through 1990. Three-quarters of these in Minnesota acquired HIV/AIDS from their mothers before birth, the others from earlier transfusions or transplants.

Members of minority groups have a far greater rate of AIDS than whites, as shown in Table 3. Although the absolute numbers of African Americans in Minnesota with AIDS is small, their proportion of all AIDS cases—one in ten—is about five times their share of the state's population.

Likewise with Hispanics (who may be of any race), whose share of the AIDS cases is more than double their share of the state's population. Minnesotans of Asian and American Indian background have a smaller share of AIDS than their population.

In Minnesota about one in seven of African American and one in ten of Hispanic AIDS cases arose from intravenous drug use.

Table 2. AIDS Cases, by Transmission

	Number of Cases			Percent of Cases		
	Male	Female	Total	Male	Female	Total
Homosexual/bisexual	677	0	677	84	0	81
Homosexual/intravenous drug use	50	0	50	6	0	6
Intravenous drug use	23	5	28	3	14	3
Heterosexual	6	17	23	1	49	3
Hemophilia/transfusion	29	7	36	4	20	4
Parent	2	4	6	0	11	1
Other/unknown	18	2	20	2	6	2
Total	805	35	840	100	100	100

Source: Minnesota Department of Health, March 1991.

Figure 2. Source of AIDS in Minnesota, Cumulative Cases 1982-90

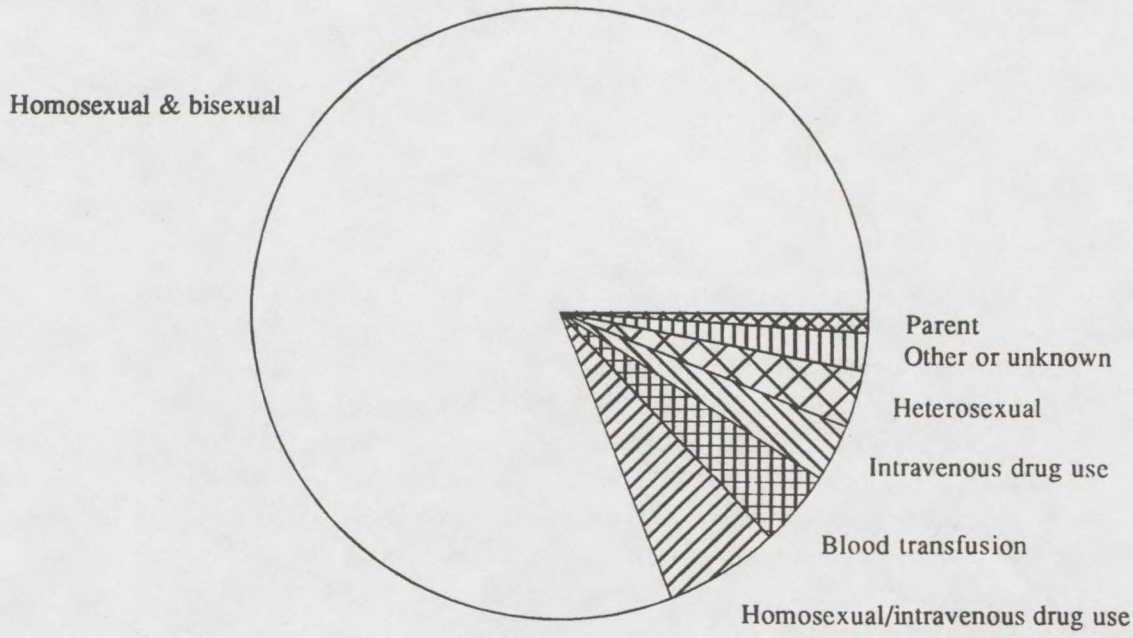


Table 3. Rate of AIDS Infection Compared to Population Totals, Minnesota, cumulative 1982-1990

Racial/Ethnic Group	Number of AIDS Cases in Minnesota	Proportion of AIDS Cases in Minnesota	Proportion of Population in Minnesota	Rate of Infection per 100,000
White, non-Hispanic	714	85.0%	93.7%	17.4
African American, non-Hispanic	89	10.6	2.1	95.7
Hispanic, any race	26	3.1	1.2	48.3
Asian	4	0.5	1.8	5.2
American Indian	7	0.8	1.1	14.5
Other	0	0.0	0.1	0.0
Total	840	100.0	100.0	19.2

Source: Minnesota Department of Health, refigured on 1990 population.

What all these figures demonstrate is that up to now, Minnesota has recorded nearly a thousand AIDS cases, the tip of an iceberg that includes at least four times as many who already carry the virus. While relatively low compared to some other states, the number continues to grow.

These numbers signal that a major new threat to the wellbeing of Minnesotans has appeared. It is serious enough to have elicited major responses from public agencies and private groups.

WHAT MINNESOTA GOVERNMENT HAS DONE ABOUT HIV/AIDS

Minnesota is an activist state. Its citizens organize collectively to try to meet problems, and this often results in an expectation that government should intervene to protect them and advance their interests. A number of government entities have acted on HIV/AIDS.

The Minnesota Legislature

The Minnesota Legislature has taken a proactive and effective role in the fight against HIV/AIDS. This has been true in terms of both the actions it has taken and the proposals it has rejected.

Recognizing the potential for a few members to advocate panicky, drastic action against the threat of a new, unknown disease, the leadership of the Minnesota Legislature responded in a uniquely creative way.

Senate majority leader Roger Moe (DFL-Ada), with full cooperation of minority leader Duane Benson (IR-Lanesboro), organized a teach-in about HIV/AIDS. They held a special session in the Senate chamber on Presidents Day 1988, which every member was expected to attend, to orient senators about HIV/AIDS. The main speaker was State Epidemiologist Michael Osterholm. What this exercise did was to provide a common base of elementary knowledge about HIV/AIDS. It gave priority to accepted public health doctrine as to what would likely be effective policy for the state to pursue.

Later the House of Representatives held a similar briefing session. The involvement of the House leadership appeared to convey less urgency and commitment than in the Senate, but the results were, though to a lesser degree, similar.

The legislature has committed substantial funds to the fight against HIV/AIDS. In fact, Minnesota is in the highest group of states in amount spent on HIV/AIDS in terms of dollars per diagnosed AIDS case, although this figure is not fully useful since most of the expenditures have been directed toward prevention and early detection. State money for AIDS programs was new money; that is, the legislature did not require reallocation of other health funds to deal with the new disease.

HIV/AIDS spending should be seen in the context of the popularity of health programs in general in Minnesota—"Anything with health in the title we pass," a leader opined. Spending on education for prevention is, it should be emphasized, especially in Minnesota, an investment, in that those who are or become impoverished by treatment for HIV/AIDS will frequently end up using Minnesota's health care programs for the poor.

Considerable state money—now more than $2 million per year—has been allocated for community-based organizations such as the Minnesota AIDS Project for education, prevention, and care programs. And, perhaps most innovatively, $400,000 of that sum was earmarked for anti-HIV/AIDS programs recommended by each of four ethnic councils—African American, Hispanic, Asian, and American Indian.

HIV/AIDS legislation not related to funding that has passed includes a "right-to-know" the status of an accident victim whose blood contacts the first-response ambulance team. Lobbyists for such groups wanted mandatory testing of the victim, but the act as passed allowed testing only with his or her consent. The argument against accident victim testing is that it is inadequate; the fact is that, if caregivers are exposed to blood, the only way they can know for sure if they have been exposed is by their own repeated testing. These health workers are eligible for free HIV testing and counseling.

The legislature also required all public schools to present a program of HIV/AIDS education. This action constituted preemption of the State Board of Education's authority, but in fact was welcomed by the board as providing legitimation for action it supported.

What the legislature did not do was in many respects as important as what it did. The eventual outcome of careful, scientific legislation was not assured. Committee chairs felt that it was always touch-and-go whether they could prevent draconian actions. Tactically, bills for massive mandatory testing or limiting AIDS education either were not brought to the floor, or if passed in the House of Representatives, were killed in the Senate (or vice versa) or in conference. When the principal proponent in the legislature of a get-tough-on-HIV/AIDS agenda was defeated for re-election in 1988, this isolated other partisans who might have thought HIV/AIDS would be an effective political issue.

But the legislature did not do everything possible against HIV/AIDS. Legislation that would speak to concerns that might encourage more widespread testing, such as specifically outlawing discrimination based on sexual orientation, was not passed, nor seriously pushed. Also, Minnesota is the only Midwestern state where sodomy is still illegal, but it must be said that other states decriminalized sodomy as a part of general revisions in the criminal law, rather than in a single-subject repeal effort. Most Minnesota proponents of such action do not want to risk likely defeat in a direct attack.

Surprisingly, for a new, dangerous, potentially volatile issue, members reported virtually no communications about HIV/AIDS from people in their districts.

A few other groups have tried to influence legislative action on HIV/AIDS. The Citizens League issued a report on AIDS in 1988. It was unusual for the Citizens League to get into what could be defined as a personal or social issue, but obviously this illustrates that the League recognized important public policy consequences of HIV/AIDS.

The conclusions of the report, *AIDS: An Individual Responsibility*, were also unusual, because the Citizens League practice in its reports is to challenge a specific governmental body to take a specific action. The HIV/AIDS report was directed primarily to individuals, recognizing that avoiding HIV/AIDS was essentially a matter of individual personal responsibility.

But the Citizens League asked for some policy actions too, specifically asking the state to repeal its criminal sodomy law and to expand its legal protection against discrimination to include sexual orientation. These positions were contested within the study committee from those who wanted more tough actions. From the other extreme, the report was criticized as not being liberal enough. It ultimately contained two minority dissents.

The report came out with a bang of publicity, then sank from sight without a trace, although it might well have strengthened the chances of moderate HIV/AIDS legislation.

Another Minnesota group has a comprehensive conservative agenda for legislative action—the Berean League, a self-styled pro-family, pro-morality group. They prepared a policy document on HIV/AIDS, stating opposition to any HIV/AIDS education as well as sex education in the schools that goes beyond the advocacy of abstinence before marriage. They preferred the conservative minority report of the Citizens League committee as an agenda for state action.

The Berean League has had a significant role in keeping gay rights legislation off the books. They instigated a flood of letters and calls to legislators when that issue came up in 1991. But the Berean League has not been successful in securing the measures against HIV/AIDS carriers they prefer.

This climate may well change with the revelation in June 1991 that a doctor with HIV/AIDS did not refrain from performing invasive procedures on patients. It is clear that increased pressure will be brought to bear in the 1992 legislative session for testing of health care providers. The most extreme position would be mandatory testing, in the face of which physicians would likely demand as a tradeoff, mandatory testing for patients as well. It is inevitable, therefore, that mandatory testing would expand from a carefully targeted to a massive universal program. Although this may be popular because superficially plausible, such action would reverse the legislature's record to this point of cautious, public-health oriented action.

As a final explanation of the legislative reaction, several leaders were especially sensitive to HIV/AIDS because of their personal acquaintance with persons suffering from that disease. Two prominent DFL activists, Dick Hanson and Bert Henningson, died of AIDS in 1987 and 1988. Likewise, Senate Minority Leader Benson knew from his days in professional football Jerry Smith, an all-pro end for the Washington Redskins who died of AIDS. A personal acquaintanceship with someone who has the disease often explains people's special concerns and efforts regarding the disease. Obviously, as the epidemic progresses, fewer policymakers will remain untouched.

Minnesota's Governors

Then-Governor Rudy Perpich responded to initial requests from the state Department of Health for emergency funding to begin anti-HIV/AIDS programs so as not to have to await the next fiscal year's appropriation process by getting an allocation approved by the Legislative Advisory Committee in October 1985.

Governor Perpich's typical administrative style was to put strong commissioners in charge of state agencies and then back them up, rather than seizing the initiative to adopt personal programs. This is not meant as criticism, for as will be seen, this meant Perpich supported a very proactive HIV/AIDS effort from the Health Department, which was not always without controversy.

Current Governor Arne Carlson as one of his first official acts issued an Executive Order barring discrimination against gays and lesbians in state government. He later co-sponsored a dinner to raise money for a gay and lesbian group advocating anti-discrimination legislation, which aroused the antipathy of conservatives at the Independent-Republican convention which was meeting at the time.

Minnesota State Government Administrative Organization

As early as 1985 eleven state agencies met in a task force on AIDS to assess the likely impact of HIV/AIDS, and to insure a coordinated budget request to the legislature. From this sprang specific programs in individual agencies.

The Minnesota Department of Health

Among state health departments, Minnesota's is much admired. Chief Epidemiologist Michael Osterholm has gained national recognition in running down the source of diseases, such as tracing toxic shock syndrome to tampons and an outbreak of salmonella to Wisconsin cheese. Because of his ability and his persona, he has acquired a formidable mystique in the legislature. Michael Moen, Director of Disease Prevention and Control, is also widely respected in the legislature, where he is the department's principal spokesman on disease control issues. These officials provided critical support in the aforementioned HIV/AIDS teach-in and subsequent successful efforts to prevent passage of counterproductive HIV/AIDS legislation.

Their confident professionalism led them to use an aggressive style in the department's efforts against HIV/AIDS, setting up a comprehensive program of testing, reporting, and contact-tracing. But the personal and political situations surrounding HIV/AIDS make it different from other diseases, and hence their particular approach in this area has been highly controversial.

The Minnesota Department of Health's (MDH) strong emphasis on testing as soon as tests were developed was the first controversy. Since there was then no treatment available, many people concerned with HIV/AIDS opposed this as a blatant invasion of privacy. But as medications were developed, nearly everyone came to agree with MDH's stress on getting people to test.

A lasting controversy, however, surrounds MDH's emphasis on reporting of names of those testing positive.

A Commissioner's Task Force on AIDS was organized in 1985. Besides public health professionals, it included representatives of the Minnesota AIDS Project. This task force reported informally in June 1986. Among the measures recommended were a "name-neutral" testing policy, specifically:

> If a person at an alternative site is HIV-antibody positive, that person will be asked for their name and the implication of giving that information will be provided to them. However, regardless of whether their name is provided, appropriate services will not be denied to them by any local or state agency.

But, in fact, the Department did not adopt a name-neutral policy; instead it continued to insist that their legal authority required the reporting of names, and that, in any event, this constituted good public policy. Some in the gay community charged that rather than adopt programs developed within the task force, the department had decided what they wanted to do in advance, and expected automatic approval.

In 1987 the task force was disbanded. Many in the gay community took this as a slap in the face. They expected to continue to be consulted. The official explanation of MDH was that the task force was just that—a temporary body to look at overall policies. Since the next step was to implement programs aimed at changing behavior, MDH in 1988 formed a new task force on HIV/AIDS to advise specifically on such. Its composition was similar to the first task force, but also included individuals with specialized knowledge of behavior formation and change, and explicit representatives of African American, Hispanic, Asian, and American Indian organizations. This task force reported in February 1989. Finally, in 1990 a third task force was named, demonstrating that indeed the task forces were meant to be temporary. This task force, working with more than 100 community representatives, was convened to make recommendations to improve care and services for persons with HIV/AIDS in Minnesota. Four subcommittees focused on issues related to mothers and children, adults, adolescents, and greater Minnesota.

Some public meetings with MDH officials speaking to gays degenerated into shouting matches. Gays decried the department's name reporting and contact tracing units as "sex police," and department members questioned the legitimacy of certain gay spokespersons. This discouraged further communication. It must be noted that gays are factionalized, and that some elements choose confrontational tactics not necessarily engaged in nor approved of by other elements.

MDH also had a major confrontation with Hennepin County. In 1990 the department threatened not to renew its contract with Hennepin County's Red Door clinic as an HIV/AIDS counseling and testing site. The Red Door advertised and practiced effective anonymity of testing, aiming to increase testing by countering fears of clients that their names might be disclosed and their contacts traced. But MDH, standing on their clear statutory authority requiring reporting of all those diagnosed with communicable diseases (which they had designated HIV/AIDS to be), and believing in the ultimate efficacy of this effort, insisted that the Red Door drop their anonymous testing option and obtain and report names of those testing positive for the HIV/AIDS.

The Red Door actually was getting names of only approximately 15-20 percent of those testing positive. MDH believed that Red Door's staff subverted the names policy, citing in contrast the approximately 75-80 percent name response received at St. Paul's Room 111 Clinic.

Not all of the difference between name-reporting rates at Red Door and Room 111 could, of course, be attributed to the attitude of the clinic staffs. The potential testees who were most fearful of being revealed might have opted, regardless of the county of their residence, to test at Red Door, since it was widely known not to press for names. Thus even had such individuals gone instead to Room 111, they could have been expected to give false names.

As the conflict continued, ultimata were delivered through formal letters, which reached the newspapers. MDH threatened to withdraw completely their support for HIV/AIDS testing at Red Door, even asking for other agencies to request designation as a counseling and testing site in place of Red Door.

The managers of Red Door resented what they saw as meddling from the state on delivery issues. The Hennepin County Board backed its own agency in the clinic fight, going so far as to consider the necessity of local funding for continued anonymous HIV/AIDS testing if the state cut off its support.

This display of brinksmanship was serious. Realistically MDH could not hope to get anyone else to inaugurate an equivalent testing program if they pulled their support from Red Door. The controversy continued over some months, and there appeared to be no attempt by state and local officeholders to intervene.

Finally, a compromise was worked out. Red Door promised to make a "good faith" effort to get names, and the department renewed the contract that provided funds for HIV/AIDS testing and counseling. MDH is still resentful about the situation, reporting that the percentage of names reported from Red Door has not gone up appreciably.

The testing-reporting-tracing program would not have been complete even if Red Door had relented. At counseling and testing sites other than Red Door, of all persons tested, not all will give their names, and only some are willing to talk to health department personnel at the test site. Relatively few of these will give the names of their contacts, and not all of those are willing to have public health officials talk with their contacts. In the end, only 5-15 percent provide names of contacts for health officials to try and locate and counsel.

A new development in the testing effort transpired in June 1991 when MDH went public with the suggestion that some 339 patients of a family physician who has HIV/AIDS be tested. On these people the doctor had performed invasive procedures while he had a rash on his arms. This "look-back" found not a single patient who tested positive for HIV. But public concern had been aroused, and the governor instructed the Commissioner of Health to make recommendations regarding HIV/AIDS among healthcare workers.

MDH reported in October 1991 that they estimated the risk of transmission from an infected healthcare worker to a patient was between 1 in 2 million and 1 in 21 million, yet they proposed new procedures be authorized:

1) that universal infection control procedures be adopted in every healthcare facility, including training, designation of responsible officials, and compulsory reporting of breaches;
2) that authority be given to the state health department to inspect all healthcare facilities for infection control (accredited hospitals are currently exempt);
3) that all health professionals doing exposure prone procedures "should know their HIV antibody status," including being voluntarily tested;
4) that HIV-positive healthcare workers report their status to their licensing board, and that testing facilities report health-care workers testing positive to the MHD (as already required) and to the licensing board;
5) that professional licensing boards adopt U.S. Centers for Disease Control (CDC) guidelines to require that HIV-positive healthcare workers stop doing exposure-prone procedures and monitor their compliance.

Thus, despite the infinitesimally small risk of transmission of HIV/AIDS from healthcare workers to patients, which should be even further reduced by more stringent infection control, MDH advocated testing and restrictions on infected health care practitioners. No doubt they hoped by this action to try to forestall even more drastic intervention from the legislature.

Despite the controversies and difficulties, MDH has played a powerful proactive role regarding HIV/AIDS. It deserves special mention for the creative way it has provided money for and worked with many local public and private agencies around the state who are involved with action programs. As such, MDH has been the major underwriter and most consistent supporter of the Minnesota AIDS Project (MAP), helping the project to become far and away the largest HIV/AIDS service organization in the country in terms of the size of the people with AIDS population it serves.

Inevitably, MDH's sponsorship of various projects has led to tensions in this area too. In trying to assure that its program goals are met, the state agency is seen by some as overly paternalistic and controlling.

For educating the general population about HIV/AIDS, MDH has composed flyers and produced videos which are available to community health agencies. They also directly sponsor ads, or fund other groups to produce and run them, in various media.

MDH has trained county and local public health personnel, and encourages local HIV/AIDS program initiatives. MDH does not provide training of other health workers, although half of the community health boards do some of this.

The highest priority for educational efforts by MDH has been groups at special risk. These ventures recognize the need for very explicit statements of why and how to be safer. The materials they produce are quite in contrast to national educational efforts, including the famed Surgeon General's HIV/AIDS brochure, which did not recommend a category of safer sex practices.

MDH has funded HIV/AIDS programs to deal with the special problems among people of color from special appropriations. The very small size of the African American population makes it very difficult for people wishing to get tested for HIV/AIDS to do so anonymously at special community health facilities, such as Pilot City on Minneapolis' north side—everyone knows everyone else. It was tried, and had to be abandoned for this reason.

The Council on Black Minnesotans works with MDH in deciding which HIV/AIDS projects should be funded by the appropriation earmarked for this minority. An example of this is the Minneapolis Urban League's program of peer counseling and group intervention. Hoping to acquire a better base of knowledge for action in this community, MDH funded a survey of African Americans and their sexual knowledge, attitudes, and behavior with respect to HIV/AIDS conducted by the University of Minnesota's Center for Urban and Regional Affairs (CURA).

Turning to Hispanics, a number of organizations compete for legitimacy as service providers for Hispanics, frequently resulting in a fragmented approach in dealing with social problems. The Spanish Speaking Affairs Council therefore required seven organizations to form an umbrella organization to handle HIV/AIDS—the Hispanic AIDS Partnership—in order to receive their special allocation. MDH sponsored a study of knowledge, attitudes, and behaviors relating to HIV/AIDS among this community also, conducted by an out-of-state group. That study revealed a high level of knowledge about HIV/AIDS, but a sense that the disease was a problem for Hispanics elsewhere rather than in Minnesota.

The Indian Affairs Council's American Indian AIDS Task Force determined that their special HIV/AIDS money should be spent to develop a more effective total STD (sexually transmitted diseases) education program in Minneapolis and on the White Earth Reservation. The program is headed by a person with HIV/AIDS—a woman—who is very open about her problem, and is believed to be very effective.

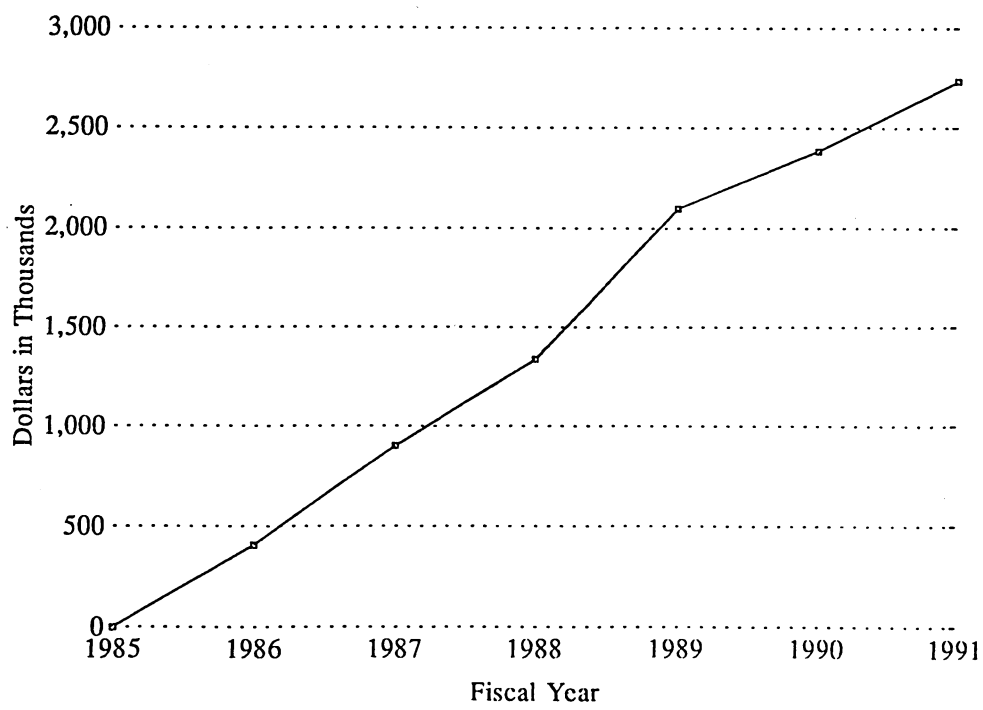
The Council on Asian/Pacific Minnesotans is the contact group for recommending HIV/AIDS programs that they believe would be effective in changing attitudes and beliefs that hinder risk reduction among this rapidly expanding segment of Minnesota's population.

An overall view of the magnitude of the HIV/AIDS expenditures of MDH is provided in Table 4. Figure 3 depicts the rise over six years to nearly S3 million per year in state funds spent through MDH. The six-year total is nearly S10 million

Table 4. Funding for AIDS through the Minnesota Department of Health (in thousands)

Fiscal Year	State Funds	Federal Funds	Grand Total
1985	S 0	S 0	S 0
1986	497	80	487
1987	900	672	1,752
1988	1,336	1,019	2,355
1989	2,097	2,237	4,621
1990	2,384	2,237	4,621
1991	2,735	2,238	4,973
Total	S9,859	S8,818	S18,677

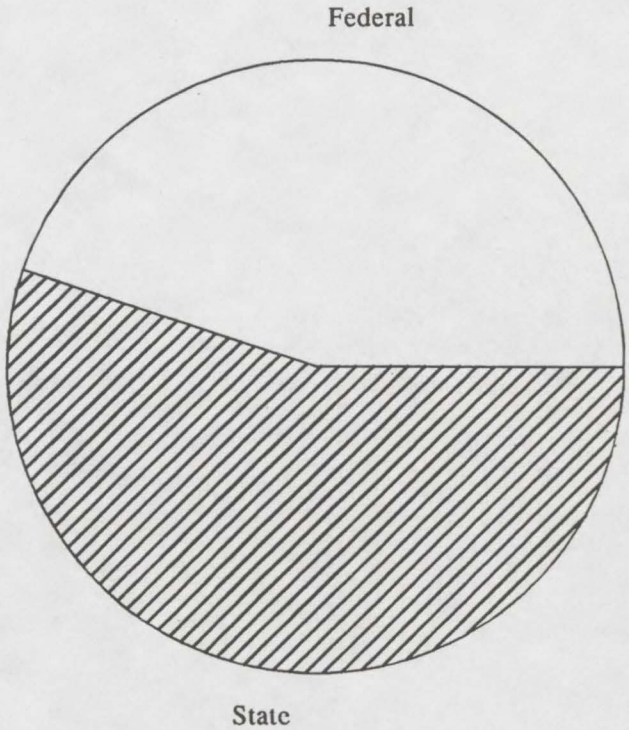
Figure 3. State Funding for AIDS (through the Minnesota Department of Health)



Almost as much federal money comes to MDH from the Centers for Disease Control, approaching a total of S9 million so far during the epidemic. The state/federal contributions illustrated in Figure 4 show that in 1991, the state provided the majority of the funds MDH spent on HIV/AIDS, which has been true every year except for 1989. This breakout also is atypical among low incidence states, some of which spend virtually no state money.

Total Minnesota Department of Health spending on HIV/AIDS so far from all sources has amounted to more than S18 million. The distribution of total spending among functions in 1991 is depicted in Figure 5. Education accounts for more than two-fifths of the outlay, with surveillance—keeping track of the spread of the

Figure 4. State and Federal Funding for AIDS in 1991 (through the Minnesota Department of Health)



disease and how many people are testing positive to the virus—accounting for almost one-fifth. Counseling and testing, and partner notification each account for one-tenth of total spending. Since the proportion of federal funds available differs among functions, and nearly three-fourths of the funding for the partner- notification program is federal money, that controversial program consumes relatively little state money.

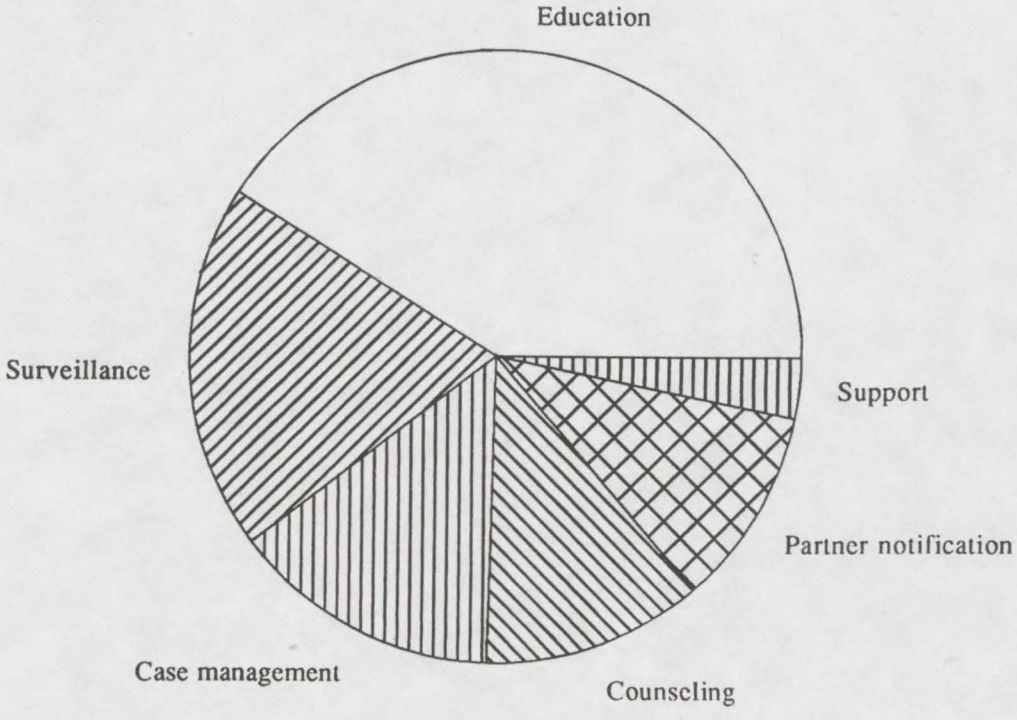
The Minnesota Department of Human Services

Minnesota's Department of Human Services (DHS) is involved with care for persons with HIV/AIDS. This is not a special responsibility, but is a part of its programs of medical assistance for the poor.

Minnesota has a generous Medicaid program—called medical assistance. Apart from seven basic federal mandates, states have a choice as to what percentage of the poor are covered, how many procedures are covered, and the payments to providers. Minnesota has chosen to participate in twenty-four of the twenty-five optional programs.

Beyond this, Minnesota, unlike the bulk of the states, also has extensive completely state/local-funded programs of medical aid for poor people of any age who do not qualify for Medicaid—called general assistance medical care (GAMC). Persons of some means must, of course, "spend down" to an income under $433 per month before they are eligible for coverage, but given the inability of people in latter stages of AIDS to work, and the high cost of drugs for treatment, a large proportion of HIV/AIDS patients will qualify. Despite Minnesota's generous health care programs, there are still individuals who will not obtain timely medical care until they are poor enough to become eligible.

Figure 5. Minnesota Department of Health AIDS Programs in 1991 (state and federal funding)



It must be pointed out that these medical assistance programs are not HIV/AIDS-specific, but are part of a generous health system for the poor. The federal government has, however, initiated some programs specifically for HIV/AIDS that are available for people with a somewhat higher income. A one-time grant of $270,000 in 1987 and the Ryan White Act of 1990 giving the state $365,000 enable Minnesota to pay for AZT and twenty-two other drugs to some 200 patients and to fund a case-management program to help people stay out of the hospital. In addition, a state-funded program to continue health insurance payments for people unable to continue working is proving cost-effective.

DHS is also the lead state agency handling drug programs. Drug programs have had to incorporate HIV/AIDS because of the spread of HIV/AIDS through intravenous drug use and the practice of trading sex for crack. This has not been easy, because persons who are suitable as drug counselors, including former addicts, are not necessarily trained in HIV/AIDS counseling.

There is less HIV/AIDS testing among intravenous drug users than among gays because the search by drug users for immediate gratification makes it difficult for them to focus on a long-term threat like HIV/AIDS. Also, because of legitimate fear of prosecution for their illegal activity, intravenous drug users are even more reluctant than gays to come to government centers. For these reasons, drug counselors would like to have a mobile testing lab in a van on the streets, so that intravenous drug users wouldn't have to make appointments in fixed facilities.

Elsewhere in the nation, controversy has erupted over proposals to provide needle-exchange (free clean needles are exchanged for used ones) in an attempt to interrupt the spread of HIV/AIDS. Opponents assert that needle-exchange would encourage drug use, even though empirical evidence suggests the reverse.

Actually, needle-exchange has not evoked much discussion in Minnesota. A smaller proportion of HIV/AIDS cases arise from intravenous drug use here than in many other states. This is partly explained by the

easier availability of needles in Minnesota. In New York, possession of hypodermic equipment for non-medical use is itself illegal. This makes needles harder to get and encourages sharing. In Minnesota, although it is technically a crime to purchase needles for illegal drug injection, in actuality anyone can buy needles if they say they are needed for diabetic treatment, or even for non-personal uses such as turkey basting. Moreover, Minnesota, joked about as the "Land of 10,000 Treatment Centers," has been in the forefront of active intervention to help drug users stop. Unlike many high incidence states, people who want to quit don't have to stand in line for months to get help. These differences from other states result in less demand for needle-exchange programs by health and drug treatment professionals in Minnesota.

The Minnesota Department of Commerce

This department regulates insurance companies and has been more vigorous in overseeing insurance companies' practices than regulators in most states. Although the state cannot tell a company they can't test for HIV/AIDS, as long as it is part of a package of tests for other risks, Minnesota has forbidden insurance companies from refusing coverage to people because they live in zip codes where gay men are concentrated or because their vocation has been stereotyped as attracting gays. The rationale is that refusing to cover a certain type of person is not measuring health risk, but is illegal discrimination.

The Minnesota Housing Finance Agency

Minnesota was one of the first states to undertake a substantial initiative in housing at the state level. A wide variety of housing programs are underway under direction of the Minnesota Housing Finance Agency (MHFA). Specific to HIV/AIDS, however, MHFA has so far participated in only one project. Through its Housing Trust Fund, it assisted the Minnesota AIDS Project with a grant to install an elevator in a house renovated and rehabilitated for sheltering HIV/AIDS patients no longer able to continue in their own homes. While modest, even this effort is more than most states have undertaken.

Under 1990 federal legislation MHFA compiled a needs assessment and program response in a comprehensive housing assistance strategy. The federal mandate required consideration of HIV/AIDS patients as well as homeless, elderly, and mentally ill persons. Almost seven million dollars is available for 1992 for all of these groups, and MHFA is working as a catalyst between HIV/AIDS service providers and developers to design programs that could be funded through this program.

The Minnesota Department of Human Rights

Minnesota has a strong anti-discrimination statute and a Department of Human Rights that has become vigorous enough to enforce it by responding to complaints. Minnesota's civil rights law does not expressly protect people from discrimination based on sexual orientation, but Minneapolis and St. Paul do have local ordinances on this subject. Minneapolis specifically included sexual orientation in its civil rights ordinance in 1974. St. Paul also passed a civil rights ordinance in 1974, but the section dealing with gay rights was overturned in a referendum in 1978. The St. Paul city council in 1990 passed another sexual orientation protection ordinance, and another referendum to try to remove it failed.

The legislature in 1989 passed a statute on hate crimes that required the reporting of crimes directed at people because they belong to a specific population class and allowing the levying of additional penalties for crimes committed for this reason. Since sexual orientation was specifically mentioned as a protected class, gays and lesbians could take this enactment as an open acknowledgement that they will receive some protection if they risk harm from being identified (through tests or treatments for HIV/AIDS, for example).

The absence of statutory language about sexual orientation and HIV/AIDS does not mean the state takes no action in this field. The Minnesota disability act has been interpreted by the Commissioner of Human Rights to cover as disabled those persons with HIV/AIDS. This information has been widely disseminated among business owners and within the gay community, and cases have been brought and successfully dealt with.

A key specific action of DHR was its pursuit of a complaint against some nursing homes who refused to admit HIV/AIDS patients. All nursing homes are now on notice that they cannot refuse to care for them, unless they apply for and receive an exemption on the grounds that they are not equipped to provide the level of care terminal HIV/AIDS patients require.

More recently—in January 1991—Minneapolis passed a domestic partners ordinance. This allows both homosexual and heterosexual unmarried couples to register as having a permanent relationship. It allows city employees bereavement benefits for domestic partners, though health benefits are excluded. One of the arguments for the measure was that it would help fight HIV/AIDS by encouraging monogamous relationships among gays.

The Minnesota Department of Education

In 1988 the State Board of Education was considering requiring HIV/AIDS education in every school when the legislature ordered it by statute (M.S.A. 121.203). The legislature granted the Department of Education $2 million to create a special AIDS Prevention and Risk Reduction Unit to implement the requirement.

School districts were given great latitude in setting up their HIV/AIDS education programs. No specific curriculum was prescribed, either by content or by grade level, and no deadline was set for instituting an HIV/AIDS instructional unit, but if a district refused to do anything, the Department of Education could have the appropriate regional Educational Cooperative Service Unit conduct a program there.

Little resistance has been reported from school staffs, but opposition arose in some communities. Anecdotal reports tell of some districts' editing sections about homosexuality and birth control out of a video on HIV/AIDS. In Mora in 1989 the school contracted for a performance by Illusion Theater called *Amazing Grace*, which deals with sex education in general, and specifically with HIV/AIDS. The night the play was to be performed for the community, a minister addressed the audience, and the performance was canceled. Then a group was organized to oppose the school district's entire sex education program. Thereupon a demonstration was staged in Mora by Twin Cities gay and lesbian activists.

The Department of Education's State Response Team, set up principally to deal with helping districts handle any case of a student with HIV/AIDS, was dispatched to Mora. Its basic strategy is to institute a cool-down time, and then to create an ad hoc committee of school and community people to work out a new plan. By putting the leading opponent of HIV/AIDS education on the committee, they hoped to coopt the opposition. This apparently worked in Mora, as a plan for sex education acceptable to all sides was instituted in 1990.

When a kindergarten through grade 12 curriculum on HIV/AIDS was presented to the Board of Education of Anoka/Hennepin school district in November 1990, after two years of preparation, 250 people from a group calling themselves "Taxpayers for Excellence in Education" challenged it. They insisted that all visual materials be removed from the curriculum, that signed permission from parents be solicited before each lesson was taught, and that a curriculum review board chosen by parents have veto power over any materials. The school board ordered the committees who drew up the curriculum to reconsider, placing two members of the opposition on each committee. This was done, and two public hearings held, whereupon the board adopted the curriculum as originally recommended.

Bills to allow parental veto of HIV/AIDS curriculum in all districts were introduced in the 1991 legislative session, and one passed the senate but was killed in conference.

Several attempts to evaluate HIV/AIDS education in Minnesota are underway. A survey of all school districts' activities was being prepared in 1991. In addition, a stratified random sample of school building activity, designed to reveal what is actually being done in the classrooms about HIV/AIDS, is also being prepared. To evaluate the effect of all this effort on the ultimate consumers—students—MDE includes HIV/AIDS matters in the Minnesota Student Survey, a 150-item questionnaire designed by the Drug-Free Schools Program to be a wide-ranging study of well-being. The first survey, in 1989, included all students in the state in grades 6, 9, and 12, reaching 91,175 of them. Since it is planned to be conducted every three years, tracing attitude and behavior changes will be possible.

Despite the substantial efforts to conduct and evaluate HIV/AIDS education, it is not possible to make a definitive statement about either how prevalent, or how effective that education is. Many observers think that existing programs of sex education in general are often not strong, so that a difficult addition like HIV/AIDS may likewise not be well handled. These people think sex education should be much more intensive. The public at large is very receptive of such efforts—more than four out of five Minnesotans supported more explicit sex education as an HIV/AIDS prevention measure, according to a poll conducted for the authors by the Minnesota Center for Survey Research—though a vocal minority is intensely opposed.

Minneapolis and Hennepin County

The Minneapolis Health Department reacted early to the HIV/AIDS epidemic by providing seed money for small innovative projects. Brian Coyle, an openly gay city council member, worked personally with other council members to enlist their support for these initiatives. (Coyle died of AIDS in 1991.)

At one time Minneapolis had a gay bathhouse. This was a center of controversy before the visible advent of HIV/AIDS, being raided by the police just before the swearing in of newly-elected liberal Mayor Don Fraser in 1979. The bathhouse closed for economic reasons just before the city began to consider forced closing as an HIV/AIDS prevention matter.

Not the city, however, but Hennepin County provides the greatest local HIV/AIDS effort. The county has a large, effective, well-paid, and nationally recognized bureaucracy. It administers the only public alternative HIV/AIDS test site in the western half of the metropolitan area, the Red Door Clinic. The Red Door clinic was already in existence as a test facility for sexually-transmitted diseases before HIV/AIDS appeared. This clinic is responsible for well over half of the HIV/AIDS tests conducted by public facilities throughout the state. The conflict in 1989 and 1990 between Hennepin County and the state Department of Health as to whether testing at the Red Door Clinic should remain anonymous has already been described. The result was that Red Door continues as a state-funded HIV/AIDS test site.

Pre-test and post-test counseling are provided at Red Door. But it does not provide medical care. Persons who test positive are strongly advised to seek medical care from private physicians, or through Hennepin County Medical Center (HCMC) if necessary, though undoubtedly and unfortunately some persons do not follow this advice.

Hennepin County runs HCMC, by far the state's largest single provider of care for persons with HIV/AIDS. The range of health services provided there is substantial, and administrators constantly pressure HCMC physicians to collect fees for services and medications rendered, though these doctors know that a number of patients, for financial reasons, do not come back for regular checkups or for preventive medications.

It is important to mention that counties in Minnesota have borne a share of the income maintenance and health costs of people with HIV/AIDS who are or become poor. Beginning in 1992, however, the state takes over the full burden of income support.

St. Paul and Ramsey County

In the eastern half of the metropolitan area, the burden of responsibility for HIV/AIDS is the reverse: the City of St. Paul provides most services, and Ramsey County has a minor role. This has historical roots, but is also more logical because St. Paul constitutes 50 percent of Ramsey's population, while Minneapolis makes up only 30 percent of Hennepin's.

Room 111, St. Paul Department of Health's existing clinic for sexually transmitted diseases, took on the HIV/AIDS work. Room 111 is seen by MDH as a model of how testing sites should operate, particularly in early intervention. Room 111 conducts beginning treatment for those who test positive for HIV/AIDS, unlike Hennepin County's Red Door Clinic.

Room 111's mode not only guarantees that the process of care actually begins, but the smooth transition between test and care at least partly explains the considerably greater success Room 111 has had in obtaining names of those testing positive for HIV/AIDS. The city of St. Paul provides about a quarter of the funds to operate Room 111. Patients pay 5 percent, and the state pays the rest.

Ramsey County's role in HIV/AIDS is to support the Visiting Nurses Association, which provides a very small percentage of the care for HIV/AIDS patients, as well as its more traditional duties. The likely dramatic increase in caseload as the 1990s progress will require significant additional spending by the county.

Though Ramsey County has been only marginally involved with HIV/AIDS, it began to show a higher profile after County Commissioner Diane Ahrens was named to the Second United States Commission on AIDS. She was instrumental in staging a commission hearing in St. Paul in 1990.

Greater Minnesota Counties

Six HIV/AIDS counseling and testing sites have been strategically located outside the metropolitan area in order to minimize the distance that persons in greater Minnesota must travel to acquire confidential testing services. These are in Rochester, St. Cloud, Mankato, Moorhead, Duluth, and Winona.

Minnesota's eighty-seven counties have organized forty-seven Community Health Service agencies to provide public health services. Each has appointed an HIV/AIDS resource person who is supposed to survey needs, work out HIV/AIDS policies, and provide community education and training. Most, but not all, of these had HIV/AIDS policies in place by 1990, but fewer than half had conducted training for all of the specific audiences that are recognized as needing special education, such as public safety and corrections staffs.

The University of Minnesota

A number of special University research efforts pertain to HIV/AIDS. The most prominent is the AIDS Clinical Trial Unit, one of a number of sites nationwide for testing experimental drugs for HIV/AIDS. Since almost all HIV/AIDS drugs currently are experimental, participation in these trials constitutes a major form of treatment for persons with HIV/AIDS, and the unit's head, Dr. Frank Rhame, is widely known for his rapport with patients. This explains the alarm in the HIV/AIDS community when it was revealed in 1991 that there was a question whether Dr. Rhame would receive tenure at the University. Also in the Medical School, the Adolescent Health Program has established a Youth and AIDS Project, a program for adolescent male homosexuals, seeking to get them to acknowledge risky sexual behavior and to develop skills to replace it with more careful actions.

A massive project funded by the National Institute for Drug Abuse was led in Minnesota by professor of family social science Richard Needle. One segment of his work involved the use of street workers to contact drug users. These workers are also trained in HIV/AIDS prevention, and work to discourage unclean needle sharing.

Training of health professionals—physicians, nurses, and allied health professionals—in dealing with HIV/AIDS is done by the federally-funded Midwest AIDS Training and Education Center located in the School of Public Health.

COMMUNITY GROUP ACTION ON HIV/AIDS

Throughout the nation, for a variety of reasons, such as the need for credibility among targeted populations, and perceived restrictions on government-produced educational materials, the primary deliverers of education and social support services to both persons with HIV/AIDS or those in high-risk groups have been newly created AIDS services organizations. In Minnesota these functions are performed by the Minnesota AIDS Project.

Minnesota AIDS Project

In Minnesota, the primary action group against HIV/AIDS is the Minnesota AIDS Project (MAP). It was formed in 1985. Gays were and are prominent on its board and among its staff. It has been—in comparative terms—well funded by MDH grants (about one-third of its income), county and municipal governments (about one-tenth each), foundation money (high at the beginning), and individual donors, as well as through its own fundraising. It has an annual budget of over S2 million, by far the largest HIV/AIDS service organization in a low-incidence state.

But MAP has never been free from controversy. Like similar agencies in other parts of the country, there was disagreement over whether it should be dominated by service professionals or activists. Relying on MDH grants opened it to charges that it had become a tool for enforcing the department's doctrine on testing and reporting. It should be noted, however, that in comparison with the turbulence in AIDs service organizations around the country, MAP is an oasis of calm.

MAP has to decide its action priorities each year, specifically what relative emphasis to give education for prevention as opposed to care of people who already had HIV/AIDS. Needless to say, persons with AIDS are most immediately concerned with the search for a cure and the need for care.

MAP's unique function is to create an extensive service delivery program using volunteers—the so-called San Francisco model. This activity is now being expanded statewide, with regional offices in Duluth, Rochester, Marshall, and St. Cloud. MAP is responsible for an 800-number hot line for HIV/AIDS information, receiving more than 600 calls per month. Both in absolute terms and especially in comparison with other AIDS service organizations, Minnesota has been well-served by MAP.

Minnesota Aids Funding Consortium

In mid-1988 a consortium was formed by the Minneapolis Foundation and the St. Paul Foundation to make sub-grants to HIV/AIDS action organizations. They raised S700,000 locally to match a S500,000 challenge grant from the National Community AIDS Partnership. In their first two years, they funded fifty-four projects in education, prevention, and care. Their focus in the last two years has been on developing leadership for policy action.

THE MEDIA AND HIV/AIDS

Everyone acknowledges the prominent role of the media in setting the public agenda and in helping to frame the public response to problems. Since HIV/AIDS was a new issue, people had to rely heavily on the media for their information base and cues as to how to react.

Star Tribune

The first story about HIV/AIDS appeared in the *Star-Tribune* in 1982. The first front-page story was in 1984. The big push of coverage came from 1985 to 1987, when concern was raised as to whether HIV/AIDS would spread massively into the white heterosexual community.

Since that time there has been less coverage. There is some sense that HIV/AIDS is a disease of "them," not "us." Newspaper officials do not admit this, but rather attribute the decline to the life cycle of issues—that the public does not want to read repetitive stories.

Yet they judge their own coverage of HIV/AIDS to be much better than on most ongoing stories. They report new developments in basic research regarding HIV/AIDS as well as the experimental trials of new drugs for treating it. At the end of each year, the *Star Tribune* publishes a wrap-around story, bringing the state and national incidence figures up to date, and reviewing developments in research and policy. The first year-end story, in 1986, was very explicit in its discussion of HIV/AIDS transmission and prevention, and the editors were surprised that they didn't receive complaints about it. Each of those stories, and some others, included addresses and phone numbers where people can get more information or services.

Pioneer Press

The St. Paul *Pioneer Press* also believes they have had good coverage of HIV/AIDS. In addition to covering many of the same things as their rival, the *Pioneer Press* points with particular pride to the fact that Jaqui Banaszynski won a Pulitzer prize for a long story in 1987, "AIDS in the Heartland," a feature on two lifetime partners, Minnesota farmers, one of whom was dying of AIDS at the time.

PUBLIC OPINION ABOUT HIV/AIDS

The Minnesota Poll first surveyed public knowledge and attitudes about HIV/AIDS in late 1987. It found a generally high level of awareness and understanding about the disease. Specifically, three-quarters of all respondents gave correct answers to at least eight of nine statements about how HIV/AIDS is transmitted. Yet one in seven still feared that using the same drinking glass could spread the disease, one in twelve believed it could be caught from toilet seats, and two of every five thought it could be obtained by *donating* blood.

Nearly one-third of Minnesotans were worried that someone in their family might get HIV/AIDS. One in eight of those with children in elementary school said they would keep their child at home if another child in the same school had AIDS. But the poll also showed that more than 90 percent of the public thought children should be taught about HIV/AIDS at school, and a majority thought this education should begin before the sixth grade.

HOW DECISIONS ON HIV/AIDS WERE MADE IN MINNESOTA

A clear pattern emerges from our review of Minnesota's response to HIV/AIDS. All levels of government and most influential private sector groups have adopted a proactive, liberal approach to HIV/AIDS. Organizations like the Berean League have been successful in blocking state gay rights legislation, but they have been generally unsuccessful in getting their initiatives enacted.

In fact, the most serious substantive argument over HIV/AIDS during the main period of our study was between activist health professionals within both the state Department of Health and Hennepin County over whether the Red Door Clinic (administered by the county but with the funds for HIV/AIDS testing coming from the state) was making a "good faith" effort to obtain and report the names of those testing positive for HIV/AIDS.

In our judgment, Minnesota's response to HIV/AIDS has largely been caused by two things: Minnesota's political culture, and the conceptualization of HIV/AIDS as primarily a public health issue.

Minnesota's Political Culture

Minnesotans have a general belief in a positive and activist role for government and special willingness to spend for health programs. In 1991, when states throughout the nation were drastically cutting spending for Medicaid and other programs serving the poor, Minnesota not only largely kept its "safety net," but the legislature passed a statewide health insurance program that would have resulted in every Minnesotan having health care coverage. Although Governor Carlson vetoed this specific plan, the fact of legislative action, and now a counter-proposal by the governor, show that most public officials believe that they are doing both the right and politically popular thing, meaning the issue is still on the agenda.

Surveys have shown that Minnesotans view spending on education, highways, and social welfare as *investments* rather than as being inherently wasteful and a drain on individual economic well-being. One can speculate that this arises from their dominant ethnic and religious backgrounds. Lutherans and Roman Catholics both historically have tended to stress collectivist values and respect for government. Under these circumstances, an activist HIV/AIDS program that received relatively generous resources and not merely supporting rhetoric should not, in retrospect, be surprising.

But when it comes to moral issues many Minnesotans are conservative. This raises the question as to why this conservatism has not resulted in a different set of HIV/AIDS policies. The answer is that policymakers in Minnesota have come generally to want to have a strong information base before launching into new ventures. When HIV/AIDS appeared, this state had a core of respected health professionals that were called upon for advice, and they were able to lay the base for action.

HIV/AIDS as a Public Health Problem

Cross-national studies of HIV/AIDS have demonstrated that public health officials in Western democracies are the single most influential group in determining HIV/AIDS policy. Moreover, when in other states measures were passed concerning HIV/AIDS that were opposed by public health professionals, like the legislation requiring mandatory testing of marriage license applicants for HIV/AIDS enacted in Illinois and Louisiana, the evidence of tremendous cost ineffectiveness presented by public health professionals led to their quick repeal.

What is the public health perspective on HIV/AIDS? Essentially, public health professionals stress the need for cooperation with representatives of those at high risk in developing a consensus on effective means for

preventing the spread of the HIV/AIDS. Their reason for stressing a partnership rather than a regulatory approach is twofold. First, the long period of being asymptomatic coupled with the absence of a cure for HIV/AIDS means that a punitive, regulatory approach such as massive mandatory testing will be counter-productive because those at high risk will not test and will therefore become "invisible" and hence not undergo the counseling and education that might lead to behavior changes.

Second, HIV/AIDS is much more difficult to transmit than most communicable diseases, and in the vast majority of cases requires the active cooperation of the person who will receive HIV/AIDS. Therefore public health professionals cannot find a professional reason for harsh measures such as quarantine.

CONCLUSIONS

- **Minnesota has mounted a very substantial, carefully thought-out governmental response to attacking HIV/AIDS.**

This was achieved by deliberate consultation between professionals in the state service and responsive legislative leaders.

With a wide array of health promotion policies already in place, only modest reorganization of agencies was required to put HIV/AIDS programs into operation. A special allocation of funds was made at the outset to get some programs underway. After that, additional appropriations for HIV/AIDS specifically enabled programs to be undertaken without requiring reallocation away from other ongoing needs. Thus no "war of the diseases"—competition for limited funds—ensued.

Establishment of HIV/AIDS programs was not achieved without friction—between state professionals and some affected groups, and between state policymakers and grantors and local government and private service delivery administrators. But these were conflicts about specific actions motivated on all sides by the desire to get effective action underway, not questions about whether something should be done, or whether HIV/AIDS was being given a sufficiently high priority.

Because Minnesota is still a relatively low HIV/AIDS incidence state, and because government action has been vigorous, there is some danger of complacency.

Major additional efforts are needed to get the other half of persons who carry HIV/AIDS to test. This will require that those who know and work with people at risk move beyond encouragement to tough concern and insistence. Organizations of targeted populations, such as gays and minorities, will have to more forthrightly advocate testing, while continuing to work against discrimination and for enhanced privacy. Remaining barriers to testing include the insistence by MDH that there is no option of anonymous testing, but this is unrealistic, especially when a testing site can't make people give their real names anyway. A van for street testing of drug users would reach additional people at risk.

Minnesota policymakers thus far have avoided responses driven by misunderstanding and panic. But new developments pose a continuing threat to this mode of action.

- **Provider organizations are in place to deliver required services to persons with HIV/AIDS.**

Minnesota has a plethora of non-governmental organizations who receive contracts from state and local government units to provide specified human services. But a new group, the Minnesota AIDS Project, came into existence to provide the wide variety of services required to care for persons with HIV/AIDS and to try to prevent other persons from acquiring it. Public/private cooperation did not have to be invented to deal with HIV/AIDS, but was no doubt easier to rapidly institute given the experience and confidence all sides have in using this method.

MAP (Minnesota AIDS Project) is well organized to provide volunteer services to persons with HIV/AIDS, constituting a major demonstration of how care for all diseases should be organized. The danger is burnout as the number of AIDS cases rises and the amount of time each person needs assistance lengthens.

The number of AIDS cases in Minnesota will be many times as high as at present. This is because large numbers of people are already known to be carrying HIV/AIDS but do not evidence symptoms of debilitating diseases. Nonetheless, health care providers and facilities in the state are adequate, even though

some health providers have balked at treating HIV/AIDS patients, as has occurred frequently elsewhere in the country.

There are, however, slippages in referrals from public HIV/AIDS test sites. This would be lessened if all test sites began the necessary treatment themselves, an action that would have to overcome possible resistance from private providers.

Fortunately, Minnesota has in place many effective programs to meet health needs. Therefore, handling the increasing HIV/AIDS caseload will require only changes in degree rather than in the kind of action required, but accommodating large cost increases will be controversial in a time of budgetary stringency.

None of this, however, should obscure the continuing problems for many in obtaining care—they will have to spend down to poverty before they are eligible for safety net assistance. More should be done to remove economic barriers so that timely care is available for people with HIV/AIDS. Ideally, this would be through a national program of universal access to health care, or pending that, some kind of state plan that would cover all health needs. If this cannot be enacted, the unique opportunities to limit the reproduction of the virus and to stave off opportunistic diseases for those with HIV/AIDS so that they can have extended productive lives could justify a special program for this disease.

- **Minnesota will not be able to completely prevent new HIV/AIDS infections.**

Gay men in Minnesota, as elsewhere, have modified their culture and individual behavior to a large, though far from full, extent in the face of the threat of HIV/AIDS. And new generations of gays must be socialized into safer behavior.

Injecting drugs is not as common in Minnesota as in some parts of the country, and the easy availability of needles makes sharing them less frequent. But drug use continues, and steroids are being injected, so there will be some continued spread of HIV/AIDS through this means. Intravenous drug use by women, or their sexual relations with drug injectors will result in an increasing number of women acquiring HIV/AIDS.

There is little evidence of any change toward safer sex among college or high school age heterosexuals. While the pool of HIV/AIDS in this group is small, it is not absent; therefore there is likely to be a slow rise in the number of HIV/AIDS infections from heterosexual relationships.

The additional HIV/AIDS educational effort among public school students may have marginal effects on their sexual behavior, but it is doubtful that the state's present HIV/AIDS educational effort will be sufficient to stop the spread of HIV/AIDS.

A fully effective attack on the disease would require intensified effort on the part of individuals, government, and the for-profit and not-for-profit sectors. A wider commitment would need to be elicited from health professionals—beyond HIV/AIDS treatment givers—to incorporate HIV/AIDS risk assessment during their professional contact with people seeking care for other purposes. The same would need to be done by professionals outside strict health settings, such as drug counselors who provide advice for those seeking help with drug abuse, and those who contact people seeking other assistance.

Widespread behavior change toward more responsible sex and drug use would require their routine incorporation into popular culture media presentations, which cannot be expected in the present climate.

Despite the fine efforts that Minnesota has made against the HIV/AIDS epidemic, the disease cannot be said to be fully under control. Understandably, this leads people to search for more dramatic ways to combat it. The great question in Minnesota concerning HIV/AIDS policy is whether the state perseveres on the basis of public health professionalism in making improvements in its efforts to combat this dread disease.

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APPENDIX

LIST OF PEOPLE INTERVIEWED FOR THIS STUDY

Sister Mary Madonna Ashton
Joanne Barr
Judy Barr
Kenyari Belfield
Duane Benson
Linda Berglin
Ellen Brown
Dan Cain
Randy Chun
Karen Clark
Stephen Cooper
Lewis Cope
Bryan Coyle
Richard Danila
Rob Daves
Sandra DuVander
Eric Engstrom
Carol Falkowski
David Feinwachs
Robert Fulton
Keith Gann
Lee Greenfield
Mike Hatch
Robert Heinrich
Margaret Heinz
Keith Henry
Curt Johnson
Howard Johnson
Robert Kane
Kathy Lamp
Deborah Loon
David Lurie
Marie Menikheim
Roger Moe
Michael Moen
Richard Needle
Terry O'Brien
Michael Osterholm
John Pacheco
Walter Parker
Linda Piccone
Frank Rhame
James Rothenberger
William Schreiber
Margaret Simpson
James Solem
Jeff Spartz
Allan Speer
Scott Strickland
Jose Trejo
Ann Wynia
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